

## General

#### Guideline Title

Mental health problems in people with learning disabilities: prevention, assessment and management.

## Bibliographic Source(s)

National Guideline Alliance. Mental health problems in people with learning disabilities: prevention, assessment and management. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Sep 14. 38 p. (NICE guideline; no. 54).

#### **Guideline Status**

This is the current release of the guideline.

This guideline meet's NGC's 2013 (revised) inclusion criteria.

# Recommendations

# Major Recommendations

Note from the National Guideline Clearinghouse (NGC): The guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

The wording used in the recommendations in this guideline (for example, words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation) and is defined at the end of the "Major Recommendations" field.

Using This Guideline with Other National Institute of Health and Care Excellence (NICE) Guidelines

Improving the Experience of Care

Use this guideline with:

•	The NICE guidelines on service user experience	in adult mental health	and patient experience in adult National
	Health Services (NHS)	, to improve the experience of care for adults	with learning disabilities and mental health
	problems		

- Recommendations for improving the experience of care for children and young people in the NICE guidelines on specific mental health problems
- The NGC summary of the NICE guideline Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, if relevant

Interventions for Mental Health Problems in People with Learning Disabilities

Use this guideline with the NICE guidelines on specific mental health problems, and take into account:

- Differences in the presentation of mental health problems
- Communication needs (see recommendation in "Communication" section below)
- Decision-making capacity (see "Consent, Capacity and Decision-making" section below)
- The degree of learning disabilities
- The treatment setting (for example, primary or secondary care services, mental health or learning disabilities services, in the community or the person's home)
- Interventions specifically for people with learning disabilities (see "Social and Physical Environment Interventions," "Psychological Interventions," "Pharmacological Interventions," and "Occupational Interventions" below).

#### Organisation and Delivery of Care and Support

Organising Effective Care

A designated leadership team of healthcare professionals, educational staff, social care practitioners and health and local authority commissioners should develop and implement service delivery systems in partnership with people with learning disabilities and mental health problems and (as appropriate) their family members, carers, self-advocates or care workers.

The designated leadership team should ensure that care is:

- Person-centred and integrated within a care programme
- Negotiable, workable and understandable for people with learning disabilities and mental health problems, their family members, carers or care workers, and staff
- Accessible and acceptable to people using the services
- Responsive to the needs and abilities of people with learning disabilities, and that reasonable adjustments (in line with the Equality Act 2010 are made if needed
- · Regularly audited to assess effectiveness, accessibility and acceptability

The designated leadership team should ensure that care pathways:

- Cover all health, social care, support and education services, and define the roles and responsibilities of each service
- Have designated staff who are responsible for coordinating:
  - How people are involved with a care pathway
  - Transition between services within and across different care pathways
- Maintain consistency of care
- Have protocols for sharing information:
  - With the person with learning disabilities and a mental health problem and their family members, carers or care workers (as appropriate)
  - With other staff (including general practitioners [GPs]) involved in the person's care
- Are focused on outcomes (including measures of quality, service user experience and harm)
- Establish clear links (including access and entry points) to other care pathways (including those for physical health problems)

The designated leadership team should ensure that young people with learning disabilities and mental health problems have in place plans that
address their health, social, educational and recreational needs (including Education, Health and Care Plans), as part of their transition to adult
services and adulthood. This planning should start when young people are aged 14 and follow the NICE guideline on transition from children's to
adults' services

The designated leadership team, together with health and social care providers, should ensure that care pathways:

- Provide access to all NICE-recommended interventions for mental health problems
- Clearly state the responsibilities of specialist learning disabilities and specialist mental health services to ensure people's needs are met

For people with learning disabilities who need acute inpatient treatment for a serious mental illness, provide treatment:

- Within a locally available service where possible and
- With staff who are skilled and knowledgeable in the care and treatment of mental health problems in people with learning disabilities

#### Staff Coordination and Communication

Staff working with people with learning disabilities and mental health problems should ensure they are fully informed about:

- The nature and degree of the learning disabilities
- The nature and severity of the mental health problem, and any physical health problems (including sensory impairments)

All people with learning disabilities and a serious mental illness should have a key worker who:

- · Coordinates all aspects of care, including safeguarding concerns and risk management
- Helps services communicate with the person and their family members, carers or care workers (as appropriate) clearly and promptly, in a
  format and language suited to the person's needs and preferences
- Monitors the implementation of the care plan and its outcomes

#### Staff Training and Supervision

Health, social care and education services should train all staff who may come into contact with people with learning disabilities to be aware:

- That people with learning disabilities are at increased risk of mental health problems
- That mental health problems may develop and present in different ways from people without learning disabilities, and the usual signs or symptoms may not be observable or reported
- That people with learning disabilities can develop mental health problems for the same reasons as people without learning disabilities (for example, because of financial worries, bereavement or relationship difficulties)
- That mental health problems are commonly overlooked in people with learning disabilities
- Where to refer people with learning disabilities and suspected mental health problems

Health and social care services should ensure that staff who deliver interventions for people with learning disabilities and mental health problems are competent, and that they:

- Receive regular high-quality supervision
- Deliver interventions based on relevant manuals, if available
- Evaluate adherence to interventions
- Take part in the monitoring of their practice (for example, by using video and audio recording, external audit and scrutiny)

Health and social care staff who deliver interventions for people with learning disabilities and mental health problems should consider using routine sessional outcome measures, including service-user-reported experience measures.

Involving People with Learning Disabilities, and Their Family Members, Carers or Care Workers, in Mental Health Assessment and Treatment

#### Communication

Take into account the person's communication needs and level of understanding throughout assessments, treatment and care for a mental health problem, and:

- Speak to the person directly rather than talking about or over them
- Use clear, straightforward and unambiguous language
- · Assess whether communication aids, an advocate or someone familiar with the person's communication methods are needed
- Make adjustments to accommodate sensory impairments (including sight and hearing impairments)
- Explain the content and purpose of every meeting or session
- Use concrete examples, visual imagery, practical demonstrations and role play to explain concepts
- · Communicate at a pace that is comfortable for the person, and arrange longer or additional meetings or treatment sessions if needed
- Use different methods and formats for communication (written, signing, visual, verbal, or a combination of these), depending on the person's preferences (see the Accessible Information Standard for guidance on ensuring people with learning disabilities receive information in formats they can understand)
- Regularly check the person's understanding
- Summarise and explain the conclusions of every meeting or session
- Check that the person has communicated what they wanted

Assess the person's capacity to make decisions throughout assessment, care and treatment for the mental health problem on a decision	⊦by-
decision basis, in accordance with the Mental Capacity Act and supporting codes of practice (see your care	). Help
people make decisions by ensuring that their communication needs are met (see the recommendation above) and (if appropriate) involved	ving a family
member, carer, care worker or other individual familiar with the person's communication abilities.	

Staff delivering care to people with learning disabilities and mental health problems should:

- Discuss the assessment process and treatment options with the person and provide information in a format and language suited to their needs, including:
  - Potential benefits
  - Potential side effects or disadvantages
  - The purpose of treatment
  - Outcome measures
- Ensure that the person understands the purpose, plan and content of any meeting or intervention before it starts, and regularly throughout
- Address any queries or concerns that the person may have at any stage
- Allow enough time for the person to make an informed choice if they have decision-making capacity, and if they do not then provide enough time for their family members, carers or care workers to contribute fully

Involving Family Members, Carers and Care Workers

Encourage and support family members, carers and care workers (as appropriate) to be actively involved throughout the assessment, care and treatment of the person's mental health problem, apart from in exceptional circumstances when an adult or young person with decision-making capacity has said that they do not want them involved.

Give family members, carers and care workers (as appropriate) information about support and interventions in a suitable format and language, including NICE's information for the public (see also the "Patient Resources" field).

#### Support and Interventions for Family Members and Carers

Advise family members and carers about their right to the following and how to get them:

- A formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health
- Short breaks and other respite care

When providing support to family members (including siblings) and carers:

- Recognise the potential impact of living with or caring for a person with learning disabilities and a mental health problem
- Explain how to access:
  - Family advocacy
  - Family support and information groups
  - Disability-specific support groups for family members or carers
- Provide skills training and emotional support, or information about how to access these, to help them take part in and support interventions
  for the person with learning disabilities and a mental health problem

If a family member or carer also has an identified mental health problem, offer:

- Interventions in line with the NICE guidelines on specific mental health problems, or
- Referral to a mental health professional who can provide interventions in line with NICE guidelines

#### Social and Physical Environment Interventions

Health, social care and education services should consider the impact of the social and physical environment on the mental health of children and young people with learning disabilities when developing care plans, and:

- Provide positive educational environments that are appropriate to their needs
- When care placements (such as birth family to foster care, foster care to adoptive placement, home to residential school/college) are required, minimise the risk of placement breakdown by taking particular care to fit these to the needs of the person
- Give special consideration and support to looked-after children and young people with learning disabilities and their foster parents or care workers, to reduce the child or young person's very high risk of developing mental health problems, and the risk of changes in their home

and carers (see the NICE guideline on looked-after children and young people	
	-

Health, social care and education services should consider the impact of the social and physical environment on the mental health of adults with learning disabilities when developing care plans, and:

- Support people to live where and with whom they want
- Encourage family involvement in the person's life, if appropriate
- Support people to get involved in activities that are interesting and meaningful to them
- Plan for and help people with any significant changes to their living arrangements

#### Annual Health Check

The following recommendations on annual health checks for people with learning disabilities build on recommendation in the "Physical Healthcare" section in the NGC summary of the NICE guideline Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, which relates to the provision of annual physical checks by GPs to all people with learning disabilities.

GPs should offer an annual health check using a standardised template to all adults with learning disabilities, and all children and young people with learning disabilities who are not having annual health checks with a paediatrician.

Involve a family member, carer or care worker (as appropriate), or a healthcare professional or social care practitioner who knows the person well, in the annual health check. Take into account that more time may be needed to complete health checks with people with learning disabilities.

Include the following in annual health checks:

- A mental health review, including any known or suspected mental health problems and how they may be linked to any physical health problems
- A physical health review, including assessment for the conditions and impairments which are common in people with learning disabilities
- A review of all current interventions, including medication and related side effects, adverse events, interactions and adherence
- An agreed and shared care plan for managing any physical health problems (including pain)

During annual health checks with adults with Down's syndrome, ask them and their family members, carers or care workers (as appropriate) about any changes that might suggest the need for an assessment of dementia, such as:

- Any change in the person's behaviour
- Any loss of skills (including self-care)
- A need for more prompting in the past few months

## Identification and Referral

Staff and others caring for people with learning disabilities should consider a mental health problem if a person with learning disabilities shows any changes in behaviour, for example:

- Loss of skills or needing more prompting to use skills
- · Social withdrawal
- Irritability
- Avoidance
- Agitation
- Loss of interest in activities they usually enjoy

Staff should consider using identification questions (adjusted as needed) as recommended in the NICE guidelines on specific mental health problems to identify common mental health problems in people with learning disabilities.

Paediatricians should explain to parents of children identified with learning disabilities that mental health problems are common in people with learning disabilities, and may present in different ways.

If a mental health problem is suspected in a person with learning disabilities, staff should conduct a triage assessment to establish an initial formulation of the problem. This should include:

• A description of the problem, including its nature, severity and duration

• An action plan including possible referral for further assessment and interventions

Refer people with learning disabilities who have a suspected serious mental illness or suspected dementia to a psychiatrist with expertise in assessing and treating mental health problems in people with learning disabilities.

#### Assessment

#### Conducting a Mental Health Assessment

A professional with expertise in mental health problems in people with learning disabilities should coordinate the mental health assessment, and conduct it with:

- The person with the mental health problem, in a place familiar to them if possible, and help them to prepare for it if needed
- The family members, carers, care workers and others that the person wants involved in their assessment
- Other professionals (if needed) who are competent in using a range of assessment tools and methods with people with learning disabilities and mental health problems

Speak to the person on their own to find out if they have any concerns (including safeguarding concerns) that they don't want to talk about in front of their family members, carers or care workers.

#### Before mental health assessments:

- Agree a clear objective, and explain it to the person, their family members, carers or care workers (as appropriate), and all professionals involved
- Explain the nature and duration of the assessment to everyone involved
- Explain the need to ask certain sensitive questions
- Address any queries or concerns that the person may have about the assessment process

#### When conducting mental health assessments, be aware:

- That an underlying physical health condition may be causing the problem
- That a physical health condition, sensory or cognitive impairment may mask an underlying mental health problem
- That mental health problems can present differently in people with more severe learning disabilities.

When conducting mental health assessments, take into account the person's:

- Level of distress
- Understanding of the problem
- · Living arrangements and settings where they receive care
- Strengths and needs

#### During mental health assessments:

- Establish specific areas of need to focus on
- Assess all potential psychopathology, and not just the symptoms and signs that the person and their family members, carers or care workers first report
- Describe the nature, duration and severity of the presenting mental health problem
- Take into account the person's cultural, ethnic and religious background
- · Review psychiatric and medical history, past treatments and response
- · Review physical health problems and any current medication, and refer to other specialists for review if needed
- Review the nature and degree of the learning disabilities, and if relevant the person's developmental history
- Assess for problems that may be associated with particular behavioural phenotypes (for example, anxiety in people with autism and
  psychosis in people with Prader-Willi syndrome), so that they can be treated
- Assess the person's family and social circumstances and environment, and recent life events
- Assess the level of drug or alcohol use as a potential problem in itself and as a factor contributing to other mental health problems
- Establish or review a diagnosis using:
  - A classification system such as Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) or International Statistical
    Classification of Diseases and Related Health Problems, 10th revised edition (ICD-10), or those adapted for learning disabilities (for
    example the Diagnostic Manual Intellectual Disability [DM-ID] or Diagnostic Criteria for Psychiatric Disorders for Use with Adults

with Learning Disabilities/Mental Retardation [DC-LD]) or

- Problem specification
- Assess whether a risk assessment is needed (see "Risk Assessment" section below)

Assess recent changes in behaviour using information from family members, carers, staff or others involved in the assessment as well as information from relevant records and previous assessments. Take into account the nature, quality and length of their relationship with the person.

Use the results of the mental health assessment to develop a written statement (formulation) of the mental health problem, which should form the basis of the care plan (see "The Mental Health Care Plan" section below) and cover:

- An understanding of the nature of the problem and its development
- Precipitating and maintaining factors
- Any protective factors
- The potential benefits, side effects and harms of any interventions
- The potential difficulties with delivering interventions
- The adjustments needed to deliver interventions
- The impact of the mental health problem and associated risk factors on providing care and treatment

Provide the person, their family members, carers or care workers (as appropriate), and all relevant professionals with a summary of the assessment:

- In an agreed format and language
- That sets out the implications for care and treatment

Give the person and their family members, carers or care workers (as appropriate) another chance to discuss the assessment after it has finished, for example at a follow-up appointment.

#### Further Assessment

Consider conducting a further assessment that covers any areas not explored by the initial assessment, if.

- New information emerges about the person's mental health problem or
- There are significant differences between the views of the person and the views of their family members, carers, care workers or staff about the problems that the assessment has focused on

#### Assessment Tools

During any mental health assessment:

- Consider using tools that have been developed or adapted for people with learning disabilities and
- Take cost into account if more than one suitable tool is available

If using tools that have not been developed or adapted for people with learning disabilities, take this into account when interpreting the results.

When conducting an assessment with a child or young person with learning disabilities, consider using tools such as the Developmental Behavior Checklist – parent version (DBC-P) or the Strengths and Difficulties Questionnaire (SDQ).

When assessing depressive symptoms in an adult with learning disabilities, consider using a formal measure of depression to monitor change over time, such as the Glasgow Depression Scale (the self-report for people with milder learning disabilities or the carer supplement for people with any degree of learning disabilities).

Consider supplementing an assessment of dementia with an adult with learning disabilities with:

- Measures of symptoms, such as the Dementia Questionnaire for People with Learning Disabilities (DLD), the Down Syndrome Dementia Scale (DSDS) or the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)
- Measures of cognitive function to monitor changes over time, such as the Test for Severe Impairment (TSI)
- Measures of adaptive function to monitor changes over time

Complete a baseline assessment of adaptive behaviour with all adults with Down's syndrome.

When conducting risk assessments with people with learning disabilities and mental health problems, assess:

- Risk to self
- Risk to others (including sexual offending)
- Risk of self-neglect
- Vulnerability to exploitation
- Likelihood and severity of any particular risk
- Potential triggers, causal or maintaining factors
- Whether safeguarding protocols should be implemented

If indicated by the risk assessment, develop a risk management plan with the person and their family members, carers or care workers (as appropriate).

Risk management plans should:

- Set out individual, social or environmental interventions to reduce risk
- Be communicated to family members, carers or care workers (as appropriate) and all relevant staff and agencies

Risk assessments and resulting risk management plans should be reviewed regularly and adjusted if risk levels change.

Mental Health Assessment During a Crisis

Conduct an initial assessment for people who are experiencing a mental health crisis, which should:

- Include an assessment of the person's mental health
- Include a risk assessment (see recommendations in "Risk Assessment" section above)
- Include identification of interventions to:
  - Help address the problem that caused the crisis
  - Minimise any associated risks
  - Bring stability to the individual and their immediate environment
  - Produce a crisis plan that sets out (using the least restrictive options possible) how to reduce the likelihood of further crises, and what to do if the person has another crisis

The Mental Health Care Plan

Develop a mental health care plan with each person with learning disabilities and a mental health problem and their family members, carers or care workers (as appropriate), and integrate it into their other care plans.

Base mental health care plans on the written statement (formulation) and include in them:

- Goals agreed with the person and the steps to achieve them
- Treatment decisions
- Agreed outcome measures that are realistic and meaningful to the person, to monitor progress
- Early warning signs of relapse or exacerbation of symptoms, if known
- Risk and crisis plans, if needed (see "Risk Assessment" and "Mental Health Assessment During a Crisis" above)
- Steps to minimise future problems

Ensure that the mental health care plan sets out the roles and responsibilities of everyone involved in delivering it, and that:

- The person can easily access all interventions and services in the plan
- It is communicated to everyone involved, including the person and their family members, carers or care workers (as appropriate)
- There is an agreement on when the plan will be reviewed

#### Psychological Interventions

Delivering Psychological Interventions for Mental Health Problems in People with Learning Disabilities

For psychological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems and take into account:

- The principles for delivering psychological interventions (see recommendations in this section) and
- The specific interventions recommended in this guideline (see "Specific Psychological Interventions" below)

Use the mental health assessment to inform the psychological intervention and any adaptations to it, and:

- Tailor it to their preferences, level of understanding, and strengths and needs
- · Take into account any physical, neurological, cognitive or sensory impairments and communication needs
- Take into account the person's need for privacy (particularly when offering interventions on an outreach basis)
- Agree how it will be delivered (for example, face-to-face or remotely by phone or computer), taking into account the person's communication needs and how suitable remote working is for them

If possible, collaborate with the person and their family members, carers or care workers (as appropriate) to:

- Develop and agree the intervention goals
- Develop an understanding of how the person expresses or describes emotions or distressing experiences
- · Agree the structure, frequency, duration and content of the intervention, including its timing, mode of delivery and pace
- Agree the level of flexibility needed to effectively deliver the intervention
- Agree how progress will be measured and how data will be collected (for example, visual representations of distress or wellbeing)

Be aware that people with learning disabilities might need more structured support to practise and apply new skills to everyday life between sessions. In discussion with the person, consider:

- Providing additional support during meetings and in the planning of activities between meetings
- Asking a family member, carer or care worker to provide support and assistance (such as reminders) to practise new skills between meetings

#### Specific Psychological Interventions

Consider cognitive behavioural therapy, adapted for people with learning disabilities (see the previous section on intervention adaptation methods), to treat depression or subthreshold depressive symptoms in people with milder learning disabilities.

Consider relaxation therapy to treat anxiety symptoms in people with learning disabilities.

Consider using graded exposure techniques to treat anxiety symptoms or phobias in people with learning disabilities.

Consider parent training programmes specifically designed for parents or carers of children with learning disabilities to help prevent or treat mental health problems in the child, and to support carer wellbeing.

Parent training programmes should:

- Be delivered in groups of parents or carers
- Be accessible (for example, take place outside normal working hours or in community settings with childcare facilities)
- Focus on developing communication and social functioning skills
- Typically consist of 8 to 12 sessions lasting 90 minutes
- Follow the relevant treatment manual
- Use all of the necessary materials to ensure consistent implementation of the programme
- · Seek parent feedback

#### Pharmacological Interventions

For pharmacological interventions for mental health problems in people with learning disabilities, refer to the NICE guidelines on specific mental health problems and take into account the principles for delivering pharmacological interventions (see the following recommendations).

For guidance on adherence and the safe and effective use of medicines, see the NICE guideline on medicines adherence	
and the NGC summary of the NICE guideline Medicines optimisation: the safe and effective use of medicines to enable the	ne best possible
outcomes	

Only specialists with expertise in treating mental health problems in people with learning disabilities should start medication to treat a mental health problem in:

- Adults with more severe learning disabilities (unless there are locally agreed protocols for shared care)
- Children and young people with any learning disabilities

Before starting medication for a mental health problem in children, young people or adults with learning disabilities:

- Take account of:
  - Potential medication interactions
  - The potential impact of medication on other health conditions
  - The potential impact of other health conditions on the medication
- When necessary consult with specialists (for example, neurologists providing epilepsy care when prescribing antipsychotic medication that
  may lower the seizure threshold), to minimise possible interactions
- Assess the risk of non-adherence to the medication regimen or any necessary monitoring tests (for example, blood tests), and the implications for treatment
- Establish a review schedule to reduce polypharmacy
- Provide support to improve adherence (see the NICE guideline on medicines adherence)
- Assess whether support from community and learning disabilities nurses is needed for physical investigations (such as blood tests)
- · Agree monitoring responsibilities, including who will carry out blood tests and other investigations, between primary and secondary care

Monitor and review the benefits and possible harms or side effects, using agreed outcome measures and taking into account communication needs. If stated in the relevant NICE guideline, use the timescales given for the specific disorder to inform the review, and adjust it to the person's needs.

When deciding the initial dose and subsequent increases, aim for the lowest effective dose. Take account of both potential side effects and difficulties the person may have in reporting them, and the need to avoid sub-therapeutic doses that may not treat the mental health problem effectively.

#### Prescribers should record:

- A summary of what information was provided about the medication prescribed, including side effects, to the person and their family members, carers or care workers (as appropriate) and any discussions about this
- When the medication will be reviewed
- Plans for reducing or discontinuing the medication, if appropriate
- Full details of all medication the person is taking, including the doses, frequency and purpose

For people with learning disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms:

- Consider reducing or discontinuing long-term prescriptions of antipsychotic drugs
- Review the person's condition after reducing or discontinuing a prescription
- Consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems
- Annually document the reasons for continuing the prescription if it is not reduced or discontinued

When switching medication, pay particular attention to discontinuation or interaction effects that may occur during titration. Only change one drug at a time, to make it easier to identify these effects.

#### Occupational Interventions

In keeping with the preferences of the person with learning disabilities and mental health problems, all staff should support them to:

- Engage in community activities, such as going to a library or sports centre
- · Access local community resources such as libraries, cinemas, cafes and leisure centres
- Take part in leisure activities, such as hobbies, which are meaningful to the person

Reasonable adjustments may be needed to do this (in line with the Equality Act 2010 ), such as a buddy system, transport, or advising local facilities on accessibility.

Actively encourage adults with learning disabilities (with or without a mental health problem) to find and participate in paid or voluntary work that is meaningful to them, if they are able.

Consider providing practical support to adults with learning disabilities (with or without a mental health problem) to find paid or voluntary work, including:

- Preparing a curriculum vitae (CV)
- Identifying personal strengths and interests
- Completing application forms
- Preparing for interviews
- · Accompanying the person to interviews
- Completing any pre-employment checks

Health and social care services should take account of an adult or young person's sensory, physical, cognitive and communication needs and the severity of their mental health problem (if any), and consider:

- Helping them to identify and overcome any possible challenges during employment
- Appointing supported employment workers to provide ongoing support to adults with learning disabilities and their employers
- Providing information and guidance to potential employers about the benefits of recruiting people with learning disabilities
- Assisting employers in making reasonable adjustments to help them to work (in line with the Equality Act 2010

#### **Definitions**

Strength of Recommendations

Some recommendations can be made with more certainty than others. The Guideline Committee (GC) makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the GC is confident that, given the information it has looked at, most people would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The GC usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally 'must' (or 'must not') is used if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The GC uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of people, an intervention will do more good than harm, and be cost effective. The GC uses similar forms of words (for example, 'Do not offer...') when they are confident that an intervention will not be of benefit for most people.

Interventions That Could Be Used

The GC uses 'consider' when confident that an intervention will do more good than harm for most people, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the person's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the person.

# Clinical Algorithm(s)

A National Institute for Health and	Care Excellence (NICE) pathway titl	ed "Mental health problems in people wit	th learning disabilities overview" is
available from the NICE Web site	. A NICE pa	athway titled "Dementia overview" is also	available from the NICE Web
site			

# Scope

# Disease/Condition(s)

Mental health problems, including common mental disorders (depression and anxiety disorders), psychoses (schizophrenia and bipolar disorder), dementias, eating disorders, alcohol and substance misuse, attachment disorders, sexually inappropriate behaviour, and other neuro-developmental conditions (autism and attention deficit hyperactivity disorders [ADHD] and any associated mental health problems)

Note: Problem behaviours (challenging behaviour, aggressive behaviour, destructive behaviour, and/or self-injurious behaviour) are not addressed in this guideline, as they are the focus of a dedicated National Institute for Health and Care Excellence (NICE) guideline on challenging behaviour and learning disabilities (see the National Guideline Clearinghouse [NGC] summary of the NICE guideline Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.

# Other Disease/Condition(s) Addressed

Learning disabilities

# **Guideline Category** Counseling Diagnosis Evaluation Management Prevention Risk Assessment Treatment Clinical Specialty Family Practice Internal Medicine **Pediatrics** Physical Medicine and Rehabilitation Preventive Medicine Psychiatry Psychology Speech-Language Pathology **Intended Users** Advanced Practice Nurses Allied Health Personnel Health Care Providers Nurses Patients Physician Assistants Physicians Psychologists/Non-physician Behavioral Health Clinicians

Public Health Departments

Speech-Language Pathologists

## Guideline Objective(s)

- To make recommendations for the prevention, identification, assessment and management of mental health problems in people with learning disabilities
- To improve access and engagement with treatment and services for people with learning disabilities
- To evaluate the role of specific physical, psychological, psychosocial and pharmacological interventions (and any combination of the above) in the treatment of mental health problems in people with learning disabilities
- To integrate the above to provide best-practice advice on the care of individuals throughout the course of their treatment
- To promote the implementation of best clinical practice through the development of recommendations tailored to the requirements of the National Health Service (NHS) in England and Wales.

## **Target Population**

- Children, young people, and adults with mild, moderate, severe or profound learning disabilities and mental health problems, and their families and carers
- People with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down's syndrome, Prader-Willi syndrome, Fragile X syndrome)

## Interventions and Practices Considered

- 1. Organisation and delivery of care and support
  - Use of a designated leadership team to organise effective care
  - Staff coordination and communication
  - Staff training and supervision
- 2. Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment
  - Taking into account the person's communication needs and level of understanding throughout assessments, treatment and care
  - Assessing the person's capacity to make decisions throughout assessment, care and treatment for the mental health problem on a decision-by-decision basis
  - Involving family members, carers and care workers
- 3. Providing support and interventions for family members and carers
- 4. Social and physical environment interventions
- 5. Annual health check that includes a mental health review; physical health review; a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence; and an agreed and shared care plan
- 6. Identification and referral for mental health problems
- 7. Assessment
  - Conducting a mental health assessment
  - Conducting further assessments as appropriate using validated tools
  - Risk assessment, including risk to self and others and risk of exploitation by others
  - Mental health assessment during a crisis
  - Developing a mental health care plan
- 8. Delivering psychological interventions
  - Cognitive behavioural therapy
  - Relaxation therapy
  - Use of graded exposure techniques
  - Parent training programs
- 9. Pharmacological interventions
  - Ensuring adherence
  - Taking into account potential medication interactions, the potential impact of medication on other health conditions, and the potential

impact of other health conditions on the medication

- Monitoring benefits and harms/side effects of medications
- Dosage (use of lowest effective dose)
- Use and discontinuation of antipsychotic drugs
- 10. Occupational interventions

## Major Outcomes Considered

- Mental health
- Problem behaviours
- Adaptive functioning
- Quality of life
- Service user and carer satisfaction
- Carer health and quality of life
- Rates of placement breakdown
- Psychiatric admissions
- Out-of-area placements
- Rates of seclusion
- · Rates of manual restraint
- Use of psychoactive medication
- Community participation
- Cost-effectiveness

# Methodology

## Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

# Description of Methods Used to Collect/Select the Evidence

Note from the National Guideline Clearinghouse (NGC): The guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

#### Review Protocols

Review questions drafted during the scoping phase were discussed by the Guideline Committee (GC) at the first few meetings and amended as necessary. The review questions were used as the starting point for developing review protocols for each systematic review. Where appropriate, the review questions were refined once the evidence had been searched and, where necessary, subquestions were generated. The final list of review questions can be found in Appendix F.

For questions about interventions, the PICO (Population, Intervention, Comparison and Outcome) framework was used to structure each question.

Questions relating to case identification and assessment tools and methods do not involve an intervention designed to treat a particular condition, and therefore the PICO framework was not used. Rather, the questions were designed to pick up key issues specifically relevant to clinical utility, for example their accuracy, reliability, safety and acceptability to the service user.

In some situations, review questions related to issues of service delivery are occasionally specified in the remit from the Department of Health/Welsh Assembly Government. In these cases, appropriate review questions were developed to be clear and concise.

For each topic, addressed by 1 or more review questions, a review protocol was drafted by the technical team using a standardised template (based on the PROSPERO database of systematic reviews in health), reviewed and agreed by the GC (all protocols are included in Appendix F).

#### Clinical Review Methods

#### Scoping Searches

A broad preliminary search of the literature was undertaken in September 2014 to obtain an overview of the issues likely to be covered by the scope, and to help define key areas. The searches were restricted to clinical guidelines, Health Technology Assessment (HTA) reports, key systematic reviews and randomised controlled trials (RCTs). A list of databases and Web sites searched can be found in Appendix H.

#### Systematic Literature Searches

After the scope was finalised, a systematic search strategy was developed to locate as much relevant evidence as possible. The balance between sensitivity (the power to identify all studies on a particular topic) and specificity (the ability to exclude irrelevant studies from the results) was carefully considered, and a decision made to utilise a broad approach to searching to maximise retrieval of evidence to all parts of the guideline. Searches were restricted to certain study designs if specified in the review protocol, and conducted in the following databases:

- Cumulative Index to Nursing and Allied Health Literature
- Cochrane Database of Abstracts of Reviews of Effects
- Cochrane Database of Systematic Reviews
- Cochrane Central Register of Controlled Trials Excerpta Medica Database (EMBASE)
- HTA database (technology assessments)
- Medical Literature Analysis and Retrieval System Online (MEDLINE)/MEDLINE In-Process
- Psychological Information Database (PsycINFO)

The search strategies were initially developed for MEDLINE before being translated for use in other databases/interfaces. Strategies were built up through a number of trial searches and discussions of the results of the searches with the review team and Guideline Committee (GC) to ensure that all possible relevant search terms were covered. In order to assure comprehensive coverage, search terms for mental health and learning disabilities were kept purposely broad to help counter dissimilarities in database indexing practices and thesaurus terms, and imprecise reporting of study populations by authors in the titles and abstracts of records. The search terms for each search are set out in full in Appendix H.

#### Reference Management

Citations from each search were downloaded into reference management software and duplicates removed. Records were then screened against the eligibility criteria of the reviews before being appraised for methodological quality. The unfiltered search results were saved and retained for future potential re-analysis to help keep the process both replicable and transparent.

#### Double-sifting

Titles and abstracts of identified studies were screened by 2 reviewers against inclusion criteria specified in the protocols, until a good inter-rater reliability was observed (percentage agreement ≥90% or Kappa statistics, K>0.60). Any disagreements between raters were resolved through discussion. Initially 10% of references were double-screened. If inter-rater agreement was good then the remaining references were screened by 1 reviewer.

Once full versions of the selected studies were acquired for assessment, full studies were usually checked independently by 2 reviewers, with any differences being resolved. For some review questions, a random sample of papers was checked for inclusion. Any studies that failed to meet the inclusion criteria at this stage were excluded.

#### Search Filters

To aid retrieval of relevant and sound studies, filters were used to limit a number of searches to systematic reviews and RCTs. The search filters for systematic reviews and RCTs are adaptations of validated filters designed by the Health Information Research Unit (HIRU) at McMaster University.

#### Date and Language Restrictions

Systematic database searches were initially conducted in November 2014 up to the most recent searchable date. Search updates were generated on a 6-monthly basis, with the final re-runs carried out in December 2015 ahead of the guideline consultation. After this point, studies were only included if they were judged by the GC to be exceptional (for example, if the evidence was likely to change a recommendation).

Although no language restrictions were applied at the searching stage, foreign language papers were not requested or reviewed, unless they were of particular importance to a review question.

Date restrictions were not applied, except for searches of systematic reviews which were limited to research published from 1999. The search for systematic reviews was restricted to the last 15 years as older reviews were thought to be less useful.

#### Other Search Methods

Other search methods involved: (a) scanning the reference lists of all eligible publications (systematic reviews, stakeholder evidence and included studies) for more published reports and citations of unpublished research; (b) sending lists of studies meeting the inclusion criteria to subject experts (identified through searches and the GC) and asking them to check the lists for completeness, and to provide information of any published or unpublished research for consideration (see Appendix E); (c) checking the tables of contents of key journals for studies that might have been missed by the database and reference list searches; (d) tracking key papers in the Science Citation Index (prospectively) over time for further useful references; (e) conducting searches in ClinicalTrials.gov for unpublished trial reports; (f) contacting included study authors for unpublished or incomplete datasets. Searches conducted for existing National Institute for Health and Care Excellence (NICE) guidelines were updated where necessary. Other relevant guidelines were assessed for quality using the AGREE (Appraisal of Guidelines for Research and Evaluation Instrument) instrument. The evidence base underlying high-quality existing guidelines was utilised and updated as appropriate.

Full details of the search strategies and filters used for the systematic review of clinical evidence are provided in Appendix H.

Study Selection and Assessment of Methodological Quality

All primary-level studies included after the first scan of citations were acquired in full and re-evaluated for eligibility at the time they were being entered into the study information database. More specific eligibility criteria were developed for each review question and are described in the relevant clinical evidence chapters and the review protocols in Appendix F. Eligible systematic reviews and primary-level studies were critically appraised for methodological quality (risk of bias) using a checklist – see The Guidelines Manual for templates (see the "Availability of Companion Documents" field). However, some checklists which were recommended in the 2014 manual update (NICE, 2014) were used (for example, for qualitative studies, for systematic reviews [Assessing the Methodological Quality of Systematic Reviews, AMSTAR, checklist] and for cross-sectional and cohort studies [the Newcastle Ottawa checklist for observational studies was used (Wells) for the epidemiological review on incidence and prevalence]) (see the "Availability of Companion Documents" field).

The eligibility of studies was confirmed by the GC. A flow diagram of the search process for selection of studies for inclusion in the clinical literature review conducted for this guideline is provided in Appendix P.

See the full version of the guideline for additional information for study selection and unpublished data.

#### Health Economics Methods

The aim of the health economics was to contribute to the guideline's development by providing evidence on the cost-effectiveness of interventions and services examined in this guideline. This was achieved by a systematic literature review of existing economic evidence in all areas covered in the guideline.

Literature on the health-related quality of life (HRQoL) of people covered by this guideline was systematically searched to identify studies reporting appropriate utility scores that could be utilised in a cost-utility analysis.

Search Strategy for Economic Evidence

Scoping Searches

A broad preliminary search of the literature was undertaken in September 2014 to obtain an overview of the issues likely to be covered by the scope, and help define key areas. Searches were restricted to economic studies and HTA reports, and conducted in the following databases:

- EMBASE
- MEDLINE/MEDLINE In-Process
- HTA database (technology assessments)
- NHS Economic Evaluation Database

Any relevant economic evidence arising from the clinical scoping searches was also made available to the health economist during the same period.

#### Systematic Literature Searches

After the scope was finalised, a systematic search strategy was developed to locate all the relevant evidence. The balance between sensitivity (the power to identify all studies on a particular topic) and specificity (the ability to exclude irrelevant studies from the results) was carefully considered, and a decision made to utilise a broad approach to searching to maximise retrieval of evidence to all parts of the guideline. Searches were restricted to economic studies and health technology assessment reports, and conducted in the following databases:

- EMBASE
- HTA database (technology assessments)
- MEDLINE/MEDLINE In-Process
- NHS Economic Evaluation Database
- PsycINFO

Any relevant economic evidence arising from the clinical searches was also made available to the health economist during the same period.

The search strategies were initially developed for MEDLINE before being translated for use in other databases/interfaces. Strategies were built up through a number of trial searches, and discussions of the results of the searches with the review team and GC to ensure that all possible relevant search terms were covered. In order to assure comprehensive coverage, search terms for the guideline topic were kept purposely broad to help counter dissimilarities in database indexing practices and thesaurus terms, and imprecise reporting of study interventions by authors in the titles and abstracts of records.

For standard mainstream bibliographic databases (EMBASE, MEDLINE and PsycINFO) search terms for the guideline topic combined with a search filter for health economic studies. For searches generated in topic-specific databases (HTA, NHS Economic Evaluation Database) search terms for the guideline topic were used without a filter. The sensitivity of this approach was aimed at minimising the risk of overlooking relevant publications, due to potential weaknesses resulting from more focused search strategies. The search terms are set out in full in Appendix I.

#### Reference Management

Citations from each search were downloaded into reference management software and duplicates removed. Records were then screened against the inclusion criteria of the reviews before being quality appraised. The unfiltered search results were saved and retained for future potential reanalysis to help keep the process both replicable and transparent.

#### Search Filters

The search filter for health economics is an adaptation of a pre-tested strategy designed by the Centre for Reviews and Dissemination. The search filter is designed to retrieve records of economic evidence (including full and partial economic evaluations) from the vast amount of literature indexed to major medical databases such as MEDLINE. The filter, which comprises a combination of controlled vocabulary and free-text retrieval methods, maximises sensitivity (or recall) to ensure that as many potentially relevant records as possible are retrieved from a search. A full description of the filter is provided in Appendix I.

#### Date and Language Restrictions

Systematic database searches were initially conducted in November 2014 up to the most recent searchable date. Search updates were generated on a 6-monthly basis, with the final re-runs carried out in December 2015. After this point, studies were included only if they were judged by the GC to be exceptional (for example, the evidence was likely to change a recommendation).

Although no language restrictions were applied at the searching stage, foreign language papers were not requested or reviewed, unless they were of particular importance to an area under review. All the searches were restricted to research published from 2000 onwards in order to obtain data relevant to current healthcare settings and costs.

#### Other Search Methods

Other search methods involved scanning the reference lists of all eligible publications (systematic reviews, stakeholder evidence and included studies from the economic and clinical reviews) to identify further studies for consideration. Full details of the search strategies and filter used for the systematic review of health economic evidence are provided in Appendix I.

#### Inclusion Criteria for Economic Studies

The following inclusion criteria were used to select studies identified by the economic searches for further consideration:

- 1. Only studies from Organisation for Economic Co-operation and Development member countries were included, as the aim of the review was to identify economic information transferable to the UK context.
- 2. Selection criteria based on types of clinical conditions and service users as well as interventions assessed were identical to the clinical literature review.
- 3. Studies were included provided that sufficient details regarding methods and results were available to enable the methodological quality of the study to be assessed, and provided that the study's data and results were extractable. Poster presentations of abstracts were excluded.
- 4. Full economic evaluations that compared 2 or more relevant options and considered both costs and consequences as well as costing analyses that compared only costs between 2 or more interventions were included in the review. Non-comparative studies were not considered in the review.
- 5. Economic studies were included if they used clinical effectiveness data from a clinical trial, a prospective or retrospective cohort study, a study with a before-and-after design, or from a literature review.

#### Results of the Systematic Search of Economic Literature

The titles of all studies identified by the systematic search of the literature were screened for their relevance to the topic (that is, economic issues and information on HRQoL). References that were clearly not relevant were excluded first. The abstracts of all potentially relevant studies (124 references) were then assessed against the inclusion criteria for economic evaluations by the health economist. Full texts of the studies potentially meeting the inclusion criteria (including those for which eligibility was not clear from the abstract) were obtained. Studies that did not meet the inclusion criteria, were duplicates, were secondary publications of 1 study, or had been updated in more recent publications were subsequently excluded. An economic evaluation conducted for a previously published NICE guideline was also included in the systematic review as eligible for this guideline.

All economic evaluations eligible for inclusion (5 studies) were then appraised for their applicability and quality using the methodology checklist for economic evaluations. Finally, those studies that fully or partially met the applicability and quality criteria set by NICE were considered at formulation of the guideline recommendations. A flow diagram of the search process for selection of studies for inclusion in the economic literature review conducted for this guideline is provided in Appendix P.

#### Number of Source Documents

See the evidence review sections in the full version of the guideline (see the "Availability of Companion Documents" field) for the number and type of studies included in the systematic review for each of the guideline review questions. See also Appendix P for a flow diagram of the search process for selection of studies, including total number of records identified through database searching, records screened, records excluded, full-text articles assessed for eligibility, studies included in review, and studies excluded from review.

# Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

# Rating Scheme for the Strength of the Evidence

Overall Quality of Outcome Evidence in Grading of Recommendations Assessment, Development and Evaluation (GRADE)

Level	Description	
High	Further research is very unlikely to change confidence in the estimate of effect.	
Moderate	Further research is likely to have an important impact on confidence in the estimate of effect and may change the estimate.	
Low	Further research is very likely to have an important impact on confidence in the estimate of effect and is likely to change the estimate.	
Very Low	Any estimate of effect is very uncertain.	

field): '+++', '+' or '-' on the basis of the assessment with the checklist; the strength of this evidence was considered to be 'strong', 'moderate', or 'weak', respectively. Refer to Developing NICE guidelines: the manual for definitions and the checklist.

## Methods Used to Analyze the Evidence

Meta-Analysis

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

## Description of the Methods Used to Analyze the Evidence

Note from the National Guideline Clearinghouse (NGC): The guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

#### Clinical Evidence

Data Extraction

Quantitative Analysis

Study characteristics, aspects of methodological quality, and outcome data were extracted from all eligible studies, using Review Manager Version 5.3.5 and an Excel-based form (see Appendices J to M).

In most circumstances, for a given outcome (continuous and dichotomous), where more than 50% of the number randomised to any group were missing or incomplete, the study results were excluded from the analysis (except for the outcome 'leaving the study early', in which case, the denominator was the number randomised). Where there were limited data for a particular review, the 50% rule was not applied. In these circumstances the evidence was downgraded (see 'Grading the Quality of Evidence' section below).

Where possible, outcome data from an intention-to-treat analysis (that is, a 'once-randomised-always-analyse' basis) were used. Where intention-to-treat had not been used or there were missing data, the effect size for dichotomous outcomes were recalculated using worse-case scenarios (for example, for positive outcomes this meant that it was assumed that the patients whose data was missing did not have the positive event). Where conclusions varied between scenarios (about the direction of effect or the confidence in the direction of effect or clinical importance), the evidence was downgraded (see 'Grading the Quality of Evidence' section below).

Where some of the studies failed to report standard deviations (for a continuous outcome), and where an estimate of the variance could not be computed from other reported data or obtained from the study author, the following approach was taken. When the number of studies with missing standard deviations was less than one-third and when the total number of studies was at least 10, the pooled standard deviation was imputed (calculated from all the other studies in the same meta-analysis that used the same version of the outcome measure). In this case, the appropriateness of the imputation was made by comparing the standardised mean differences (SMDs) of those trials that had reported standard deviations against the hypothetical SMDs of the same trials based on the imputed standard deviations. If they converged, the meta-analytical results were considered to be reliable.

When the conditions above could not be met, standard deviations were taken from another related systematic review (if available). In this case, the results were considered to be less reliable.

Also for continuous outcomes, final scores in each group were the preferred outcome for extraction. However, if final or change scores (from baseline) were not reported for each group in a study (for example, the study reported an F-value, *p*-value or t-value), the SMD was estimated, if possible, using a statistical calculator.

The meta-analysis of survival data, such as time to any mood episode, was based on log hazard ratios and standard errors. Since individual participant data were not available in included studies, hazard ratios and standard errors calculated from a Cox proportional hazard model were extracted. Where necessary, standard errors were calculated from confidence intervals (CIs) or p value according to standard formulae. Data were summarised using the generic inverse variance method using Review Manager.

Consultation with another reviewer or members of the Guideline Committee (GC) was used to overcome difficulties with coding. Data from studies

included in existing systematic reviews were extracted independently by 1 reviewer and cross-checked with the existing dataset. Where possible, 2 independent reviewers extracted data from new studies. Where double data extraction was not possible, data extracted by 1 reviewer was checked by the second reviewer. Disagreements were resolved through discussion. Where consensus could not be reached, a third reviewer or GC members resolved the disagreement. Masked assessment (that is, blind to the journal from which the article comes, the authors, the institution and the magnitude of the effect) was not used since it is unclear that doing so reduces bias.

The analyses performed for existing systematic reviews incorporated into the guideline were not amended unless the GC considered that additional important aspects needed to be taken into consideration. For example, this could include stratifying data, conducting additional analyses, or using different results from the primary studies in a given analysis. Otherwise, the analyses were not amended.

#### Evidence Synthesis

The method used to synthesise evidence depended on the review question and availability and type of evidence (see Appendix F for full details). Briefly, for questions about the psychometric properties of instruments, reliability, validity and clinical utility were synthesised narratively based on accepted criteria. For questions about test accuracy, bivariate test accuracy meta-analysis would have been conducted but there was not enough data to conduct these types of meta-analyses. For questions about the effectiveness of interventions, standard meta-analysis was used where appropriate, otherwise narrative methods were used with clinical advice from the GC. In the absence of high-quality research, formal and informal consensus processes were used.

#### Grading the Quality of Evidence

For questions about the effectiveness of interventions and the organisation and delivery of care, the Grading of Recommendations Assessment, Development and Evaluation RADE) approach was used to grade the quality of evidence from group comparisons for each outcome. The technical team produced GRADE evidence profiles (see below) using the GRADE guideline development tool, following advice set out in the GRADE handbook. All staff doing GRADE ratings were trained, and calibration exercises were used to improve reliability.

For questions about epidemiology, methodology checklists (see Appendix M) were used to assess the risk of bias at the study level, and this information was taken into account when interpreting the evidence. For both types of questions, an overall quality rating was given to each study:

- Epidemiological studies were rated individually as recommended in the Guidelines Manual (2012) (see the "Availability of Companion Documents" field): '+++', '++' or '--' on the basis of the assessment with the checklist; the strength of this evidence was considered to be 'strong', 'moderate', or 'weak', respectively.
- Diagnostic accuracy: while the Quality Assessment for Diagnostic Studies (QUADAS) framework does not provide an overall quality index for each study, this was deemed important to assist interpretation of the data on tools to augment assessment of mental health problems. The guideline authors adopted the terminology used within GRADE (high, moderate, low or very low quality evidence). For each of the first 3 domains (patient selection, index test, reference standard) they used the 'risk of bias' and 'concerns about applicability' ratings (low, unclear and high risk for each) to create a 3x3 table (see Table 4 in the full version of the guideline). For domain 4 (flow and timing), which has only a 'risk of bias' rating, the same method was used, but 'risk of bias' was entered on both axes. The authors then used the 4 total domain ratings to generate an overall quality index. For the overall quality rating they took the mode classification and upgraded or downgraded from that point; that is, if a study had 2 ratings of 'high', one of 'moderate' and one of 'very low', then the final quality rating would be 'moderate'.

The analyses performed for existing systematic reviews incorporated into the guideline were not amended unless the GC considered that additional important aspects needed to be taken into consideration. For example, this could include stratifying data, conducting additional analyses, or using different results from the primary studies in a given analysis. Otherwise, the analyses were not amended.

#### Evidence Profiles

A GRADE evidence profile was used to summarise both the quality of the evidence and the results of the evidence synthesis for each 'critical' and 'important' outcome (see Table 5 in the full version of the guideline for completed evidence profiles). The GRADE approach is based on a sequential assessment of the quality of evidence, followed by judgment about the balance between desirable and undesirable effects, and subsequent decision about the strength of a recommendation.

Within the GRADE approach to grading the quality of evidence, the following is used as a starting point:

- Randomised controlled trials (RCTs) without important limitations provide high-quality evidence.
- Observational studies without special strengths or important limitations provide low-quality evidence.

For each outcome, quality may be reduced depending on 5 factors: limitations, inconsistency, indirectness, imprecision and publication bias. For

the purposes of the guideline, each factor was evaluated using criteria provided in Table 6 in the full version of the guideline.

For observational studies without any reasons for down-grading, the quality may be up-graded if there is a large effect, all plausible confounding would reduce the demonstrated effect (or increase the effect if no effect was observed), or there is evidence of a dose-response gradient (details would be provided under the 'other' column).

Each evidence profile includes a summary of findings: number of participants included in each group, an estimate of the magnitude of the effect, and the overall quality of the evidence for each outcome. Under the GRADE approach, the overall quality for each outcome is categorised into 1 of 4 groups (high, moderate, low, very low) (see the "Rating Scheme for the Strength of the Evidence" field).

#### Presenting Evidence to the Guideline Committee

Study characteristics tables and, where appropriate, forest plots generated with Review Manager Version 5.3 and GRADE summary of findings tables (see example in Table 7 of the full version of the guideline) were presented to the GC. Where meta-analysis was not appropriate and/or possible, the reported results from each primary-level study were reported in the study characteristics table and presented to the GC. The range of effect estimates were included in the GRADE profile, and where appropriate, described narratively.

#### Summary of Findings Tables

Summary of findings tables generated from GRADEpro were used to summarise the evidence for each outcome and the quality of that evidence (see Table 7 in the full version of the guideline). The tables provide anticipated comparative risks, which are especially useful when the baseline risk varies for different groups within the population.

Many of the study outcomes that were of interest were extractable only as standardised mean differences (SMDs). Although it is technically possible to back-convert SMDs to the original outcome measure for interpretation, this was not felt to be a helpful approach in this case. The GC are apt at making decisions based on SMDs using the recommended interpretation of Cohen's effect size. Additionally the there was no familiar instrument that was considered useful for calculating mean differences (MDs) and to do so would have introduced a risk of bias by only using the results from 1 study to calculate baseline risk. Where the GC felt that effects were of sufficient magnitude to be clinically important this is described within the Linking Evidence to Recommendations (LETR) tables.

#### Extrapolation

When answering review questions, if there is no direct evidence from a primary dataset, based on the initial search for evidence, it may be appropriate to extrapolate from another data set, using that dataset as indirect evidence. In this situation, the following principles were used to determine when to extrapolate:

- A primary dataset is absent, of particularly high risk of bias or is judged to be not relevant to the review question under consideration, and
- A review question is deemed by the GC to be important, such that in the absence of direct evidence, other data sources should be considered, and
- Non-primary data source(s) is in the view of the GC available, which may inform the review question

See Section 3.5.6 in the full version of the guideline for more information on data extrapolation.

Method Used to Answer a Review Question in the Absence of Appropriately Designed, High-Quality Research

In the absence of appropriately designed, high-quality research (including indirect evidence where it would be appropriate to use extrapolation), both formal and informal consensus processes were adopted.

#### Health Economics

The aim of the health economics was to contribute to the guideline's development by providing evidence on the cost-effectiveness of interventions and services examined in this guideline. This was achieved by a systematic literature review of existing economic evidence in all areas covered in the guideline.

Economic modelling was planned to be undertaken in areas with likely major resource implications, where the current extent of uncertainty over cost-effectiveness was significant and economic analysis was expected to reduce this uncertainty, in accordance with The Guidelines Manual (see the "Availability of Companion Documents" field). Prioritisation of areas for economic modelling was a joint decision between the Health Economist and the GC. The rationale for prioritising review questions for economic modelling was set out in an economic plan agreed between NICE, the GC, the Health Economist and the other members of the technical team. The following economic questions were selected as key issues that were addressed by economic modelling:

- Interventions to prevent mental health problems in people with learning disabilities
- Interventions to reduce and manage mental health problems in people with learning disabilities
- Organisation and delivery of care for people with learning disabilities and mental health problems or at risk for mental health problems

In addition, literature on the health-related quality of life (HRQoL) of people covered by this guideline was systematically searched to identify studies reporting appropriate utility scores that could be utilised in a cost-utility analysis.

The identified clinical evidence on the areas prioritised for economic modelling was very sparse and did not allow for the construction of a robust and informative economic model. Therefore, no economic modelling was carried out for this guideline. Nevertheless, the GC took into consideration resource implications and anticipated cost-effectiveness of interventions and services for people with learning disabilities and mental health problems or at risk for mental health problems when making recommendations.

Applicability and Quality Criteria for Economic Studies

All economic papers eligible for inclusion were appraised for their applicability and quality using the methodology checklist for economic evaluations recommended in The Guidelines Manual (NICE, 2014). All studies that fully or partially met the applicability and quality criteria described in the methodology checklist were considered during the guideline development process. The completed methodology checklists for all economic evaluations considered in the guideline are provided in Appendix Q.

#### Methods Used to Formulate the Recommendations

Expert Consensus (Nominal Group Technique)

Informal Consensus

## Description of Methods Used to Formulate the Recommendations

Note from the National Guideline Clearinghouse (NGC): The guideline was developed by the National Guideline Alliance (NGA) on behalf of the National Institute for Health and Care Excellence (NICE). See the "Availability of Companion Documents" field for the full version of this guidance and related appendices.

#### Methods Used to Develop This Guideline

#### Overview

The development for most of this guideline followed The Guidelines Manual (NICE, 2012), but some sections have used the 2014 version of the manual (see the "Availability of Companion Documents" field). A team of healthcare professionals, social care professionals, education professionals, lay representatives and technical experts known as the Guideline Committee (GC), with support from the National Collaborating Centre for Mental Health (NCCMH) staff, undertook the development of a person-centred, evidence-based guideline. There are 7 basic steps in the process of developing a guideline:

- 1. Define the scope, which lays out exactly what will be included (and excluded) in the guidance.
- 2. Define review questions that cover all areas specified in the scope.
- Develop a review protocol for each systematic review, specifying the search strategy and method of evidence synthesis for each review question.
- 4. Synthesise data retrieved, guided by the review protocols.
- 5. Produce evidence profiles and summaries using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system.
- 6. Consider the implications of the research findings for clinical practice and reach consensus decisions on areas where evidence is not found.
- 7. Answer review questions with evidence-based recommendations for clinical practice.

The clinical practice recommendations made by the GC are therefore derived from the most up-to-date and robust evidence for the clinical and cost-effectiveness of the interventions and services covered in the scope. Where evidence was not found or was inconclusive, the GC adopted both formal and informal methods to reach consensus on what should be recommended, factoring in any relevant issues. In addition, to ensure a service user and carer focus, focus groups were also conducted, and the concerns of service users and carers regarding health and social care have been highlighted and addressed by recommendations agreed by the whole GC.

#### The Scope

Topics are referred by National Health Service (NHS) England and the letter of referral defines the remit, which defines the main areas to be covered. The NCCMH developed a scope for the guideline based on the remit (see Appendix A). The purpose of the scope is to:

- Provide an overview of what the guideline will include and exclude
- Identify the key aspects of care that must be included
- Set the boundaries of the development work and provide a clear framework to enable work to stay within the priorities agreed by NICE
  and the NCCMH, and the remit from the Department of Health
- Inform the development of the review questions and search strategy
- Inform professionals and the public about expected content of the guideline
- Keep the guideline to a reasonable size to ensure that its development can be carried out within the allocated period

An initial draft of the scope was sent to registered stakeholders who had agreed to attend a scoping workshop. The workshop was used to:

- Obtain feedback on the selected key clinical issues
- Identify which population subgroups should be specified (if any)
- Seek views on the composition of the GC
- Encourage applications for GC membership

The draft scope was subject to consultation with registered stakeholders over a 4-week period. During the consultation period, the scope was posted on the NICE Web site. Comments were invited from stakeholder organisations The NCCMH and NICE reviewed the scope in light of comments received, and the revised scope was signed off by NICE.

#### The Guideline Committee

During the consultation phase, members of the GC were appointed by an open recruitment process. GC membership consisted of: professionals in psychiatry, clinical psychology, speech and language therapy, physiotherapy, paediatrics and general practice; academic experts in education, psychiatry and psychology; commissioning managers; and carers and representatives from service user and carer organisations. The guideline development process was supported by staff from the National Collaborating Centre for Mental Health (NCCMH), who undertook the clinical and health economic literature searches, reviewed and presented the evidence to the GC, managed the process, and contributed to drafting the guideline.

#### Guideline Committee Meetings

There were 12 GC meetings, held between October 2014 and January 2016. During each day-long GC meeting, in a plenary session, review questions and clinical and economic evidence were reviewed and assessed, and recommendations formulated.

#### Service Users and Carers

The GC included 3 carers members who contributed as full GC members to writing the review questions, providing advice on outcomes most relevant to service users and carers, helping to ensure that the evidence addressed their views and preferences, highlighting sensitive issues and terminology relevant to the guideline, and bringing service user research to the attention of the GC. Services user involvement was secured through a series of focus groups which were run in collaboration with the British Institute for Learning Disabilities. Input from both service users and carers was central to the development of the guideline and they contributed to writing the guideline's introduction and the recommendations from the service user and carer perspective.

#### Expert Advisers

Expert advisers, who had specific expertise in 1 or more aspects of treatment and management relevant to the guideline, assisted the GC, commenting on specific aspects of the developing guideline and making presentations to the GC. Appendix C lists those who agreed to act as expert advisers.

#### National and International Experts

National and international experts in the area under review were identified through the literature search and through the experience of the GC members. These experts were contacted to identify unpublished or soon-to-be published studies, to ensure that up-to-date evidence was included in the development of the guideline. They informed the GC about completed trials at the pre-publication stage, systematic reviews in the process of being published, studies relating to the cost effectiveness of treatment and trial data if the GC could be provided with full access to the complete trial report. Appendix E lists researchers who were contacted.

#### Method Used to Answer a Review Question in the Absence of Appropriately Designed, High-Quality Research

In the absence of appropriately designed, high-quality research (including indirect evidence where it would be appropriate to use extrapolation), both formal and informal consensus processes were adopted.

#### Formal Method of Consensus

The modified nominal group technique was chosen due to its suitability within the guideline development process. The nominal group technique requires participants to indicate their agreement with a set of statements about the intervention(s) of concern. These statements were developed by the NCCMH technical team drawing on the available sources of evidence on the methods of delivery and outcomes of the interventions. These sources of evidence could be supplemented by advice from external experts in the intervention(s). Agreement with the statements were rated on a 9-point Likert scale, where 1 represented least agreement and 9 represented most agreement. In the first round participants indicated the extent of their agreement with the statements and also provided written comment on their reason for any disagreement and how the statement could be modified.

In round 1, members were presented with an overview of the modified nominal group technique, a short summary of the available evidence, a consensus questionnaire containing the statements and instructions on the use of the questionnaire. Members were asked to rate their agreement with the statements taking into account the available evidence and their expertise. For the purpose of determining agreement, ratings were grouped into 3 categories to calculate the percentage agreement: 1–3 (inappropriate strategy), 4–6 (uncertain), or 7–9 (appropriate strategy or adaptation).

At the subsequent GC meeting, anonymised distributions of responses to each statement were given to all members, together with members' additional comments and a ranking of statements based on consensus percentage agreement. Those statements with 80% or greater agreement were used to inform the drafting of recommendations, where appropriate taking into account the initial comments from and subsequent discussions with the GC.

For statements where there were 60% to 80% agreement a judgement was made based on the nature of the comments from the GC. If it appeared from the comments that the general principle included within the statement was agreed but that the comments could be addressed with some minor amendments incorporating the comments, the statements were used to inform the development of recommendations. Other statements that fell within this range were re-drafted based on the comments from the first rating and re-rated as in round 1 (round 2). If agreement at 80% or above on the re-rated was achieved, the statements were used to inform recommendations. Those that did not were discarded.

Any distribution of ratings with less than 60% agreement in round 1 was generally regarded as no consensus and discarded, unless obvious and addressable issues were identified from the comments.

#### Informal Method of Consensus

The informal consensus process involved a group discussion of what is known about the issues. The views of GC were synthesised narratively by a member of the review team, and circulated after the meeting. Feedback was used to revise the text, which was then included in the appropriate evidence review chapter.

#### From Evidence to Recommendations

Once the clinical and health economic evidence was summarised, the GC drafted the recommendations. In making recommendations, the GC took into account the trade-off between the benefits and harms of the intervention/instrument, as well as other important factors, such as the relative value of different outcomes reported in the evidence, quality of the evidence, trade-off between net health benefits and resource use, values and experience of the GC and society, current clinical practice, the requirements to prevent discrimination and to promote equality4, and the GC's awareness of practical issues.

Finally, to show clearly how the GC moved from the evidence to the recommendations, each chapter (or sub-section) has a section called 'recommendations and link to evidence'. Underpinning this section is the concept of the 'strength' of a recommendation. This takes into account the quality of the evidence but is conceptually different. Some recommendations are 'strong' in that the GC believes that the vast majority of healthcare professionals and service users would choose a particular intervention they considered the evidence in the same way that the GC has. This is generally the case if the benefits clearly outweigh the harms for most people and the intervention is likely to be cost effective. However, there is often a closer balance between benefits and harms, and some service users would not choose an intervention whereas others would. This may happen, for example, if some service users are particularly averse to some side effect and others are not. In these circumstances the recommendation is generally weaker, although it may be possible to make stronger recommendations about specific groups of service users. The strength of each recommendation is reflected in the wording of the recommendation, rather than by using ratings, labels or symbols (see the "Rating Scheme for the Strength of the Recommendations" field).

Where the GC identified areas in which there are uncertainties or where robust evidence was lacking, they developed research recommendations. Those that were identified as 'high priority' were developed further in the NICE version of the guideline, and presented in Appendix G.

## Rating Scheme for the Strength of the Recommendations

#### Strength of Recommendations

Some recommendations can be made with more certainty than others. The Guideline Committee (GC) makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the GC is confident that, given the information it has looked at, most patients would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

Interventions That Must (or Must Not) Be Used

The GC usually uses 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally the GC uses 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

Interventions That Should (or Should Not) Be Used – a 'Strong' Recommendation

The GC uses 'offer' (and similar words such as 'refer' or 'advise') when confident that, for the vast majority of patients, an intervention will do more good than harm, and be cost effective. Similar forms of words (for example, 'Do not offer...') are used when the GC is confident that an intervention will not be of benefit for most patients.

Interventions That Could Be Used

The GC uses 'consider' when confident that an intervention will do more good than harm for most patients, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to have the intervention at all, is more likely to depend on the patient's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the patient.

## Cost Analysis

#### Presentation of Economic Evidence

The economic evidence considered in the guideline is provided in the respective evidence chapters of the full version of the guideline, following presentation of the relevant clinical evidence. The references to included studies and the respective evidence tables with the study characteristics and results are provided in Appendix R in the full guideline appendices (see the "Availability of Companion Documents" field). Characteristics and results of all economic studies considered during the guideline development process are summarised in economic evidence profiles provided in Appendix S. See the "Availability of Companion Documents" field for the full version of the guideline and related appendices.

#### Method of Guideline Validation

External Peer Review

Internal Peer Review

# Description of Method of Guideline Validation

#### Stakeholder Contributions

Professionals, service users, and companies have contributed to and commented on the guideline at key stages in its development. Stakeholders for this guideline include:

- Service user and carer stakeholders: national service user and carer organisations that represent the interests of people whose care will be covered by the guideline
- Local service user and carer organisations: but only if there is no relevant national organisation

- Professional stakeholders' national organisations: that represent the healthcare professionals who provide the services described in the guideline
- Commercial stakeholders: companies that manufacture drugs or devices used in treatment of the condition covered by the guideline and whose interests may be significantly affected by the guideline
- Providers and commissioners of health services in England
- Statutory organisations: including the Department of Health
- Government, National Health Service (NHS) Quality Improvement Scotland, the Care Quality Commission and the National Patient Safety Agency
- · Research organisations: that have carried out nationally recognised research in the area

The National Institute for Health and Care Excellence (NICE) clinical guidelines are produced for the NHS in England, so a 'national' organisation is defined as 1 that represents England, or has a commercial interest in England.

Stakeholders have been involved in the guideline's development at the following points:

- Commenting on the initial scope of the guideline and attending a scoping workshop held by NICE
- Commenting on the draft of the guideline

#### Validation of the Guideline

Registered stakeholders had an opportunity to comment on the draft guideline, which was posted on the NICE Web site during the consultation period. Following the consultation, all comments from stakeholders and experts (see Appendix D in the full guideline appendices [see the "Availability of Companion Documents" field]) were responded to, and the guideline updated as appropriate. NICE also reviewed the guideline and checked that stakeholders' comments had been addressed.

Following the consultation period, the Guideline Committee (GC) finalised the recommendations and the National Guideline Alliance (NGA) produced the final documents. These were then submitted to NICE for a quality assurance check. Any errors were corrected by the NGA, then the guideline was formally approved by NICE and issued as guidance to the NHS in England.

# Evidence Supporting the Recommendations

# Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

See "Recommendations and link to evidence" sections in the full version of the guideline for detailed discussion of the evidence supporting each recommendation.

# Benefits/Harms of Implementing the Guideline Recommendations

#### Potential Benefits

- Preventing mental health problems in people with learning disabilities
- Support, and recovery for persons with learning disabilities who have mental health problems
- Support for family and paid carers

See the "Trade-off between clinical benefits and harms" sections in the full version of the guideline (see the "Availability of Companion Documents" field) for details about benefits of specific interventions.

## **Potential Harms**

Co-morbidities are not only important regarding recognition and diagnosis of other conditions, they also impact on medical treatment. Multiple conditions can result in multiple prescriptions, and several of the commonly experienced conditions are treated with drugs that bring a cholinergic

burden, so together compounding cholinergic burden with potential adverse consequences such as impairing cognition. Polypharmacy can introduce both medication-medication interactions, and medication-disease interactions (in addition to single medication side-effects), with adverse consequences, hence the crucial role of regular medication review, and using the minimal effective doses of medications. As people with learning disabilities may have difficulties expressing any new symptoms or side effects they are experiencing, this is particularly important. Indeed, most protocols or care pathways are designed for single conditions, and so are less relevant for a person with multiple morbidities, where deliberate deviations from single-disease protocols may well be in the person's best interest and highly individualised care is typically needed.

See the "Trade-off between clinical benefits and harms" sections in the full version of the guideline (see the "Availability of Companion Documents" field) for details about harms of specific interventions.

# **Qualifying Statements**

## **Qualifying Statements**

- The recommendations in this guideline represent the view of the National Institute for Health and Care Excellence (NICE), arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.
- Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and
  their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing
  services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity
  and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with
  those duties.
- NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh
  Government, Scottish Government, and Northern Ireland Executive. All NICE guidance is subject to regular review and may be updated or
  withdrawn.

# Implementation of the Guideline

# Description of Implementation Strategy

Putting This Guideline into Practice

The National Institute for Health and Care Excellence (NICE) has produced tools and resources to help put this guideline into practice.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. Raise awareness through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

- 2. Identify a lead with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.
- 3. Carry out a baseline assessment against the recommendations to find out whether there are gaps in current service provision.
- 4. Think about what data you need to measure improvement and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.
- 5. Develop an action plan, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.
- 6. For very big changes include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.
- 7. Implement the action plan with oversight from the lead and the project group. Big projects may also need project management support.
- 8. Review and monitor how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See into practice
pages for more information.
Also see Leng G. Moore V. Abraham S. editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley

# Implementation Tools

Clinical Algorithm

Mobile Device Resources

Patient Resources

Resources

For information about availability, see the Availability of Companion Documents and Patient Resources fields below.

# Institute of Medicine (IOM) National Healthcare Quality Report Categories

#### IOM Care Need

Getting Better

Living with Illness

Staying Healthy

#### IOM Domain

Effectiveness

Patient-centeredness

# Identifying Information and Availability

Bibliographic Source(s)

National Guideline Alliance. Mental health problems in people with learning disabilities: prevention, assessment and management. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Sep 14. 38 p. (NICE guideline; no. 54).

## Adaptation

Not applicable: The guideline was not adapted from another source.

#### Date Released

2016 Sep 14

## Guideline Developer(s)

National Guideline Alliance - National Government Agency [Non-U.S.]

## Source(s) of Funding

This guideline has been commissioned by the National Institute for Health and Care Excellence (NICE).

## Guideline Committee

Guideline Committee (GC)

# Composition of Group That Authored the Guideline

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#### Financial Disclosures/Conflicts of Interest

At each meeting, all GC members declared any potential conflicts of interest (see Appendix B in the full guideline appendices [see the "Availability of Companion Documents" field]), and service user and carer concerns were routinely discussed as a standing agenda item. Refer to Appendix B for full discussion of the conflict of interest policy.

# This is the current release of the guideline. This guideline meet's NGC's 2013 (revised) inclusion criteria. Guideline Availability . Also available for download in Available from the National Institute for Health and Care Excellence (NICE) Web site ePub and eBook formats from the NICE Web site Availability of Companion Documents The following are available: Mental health problems in people with learning disabilities: prevention, assessment and management. Full guideline. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Sep. 382 p. (NICE guideline; no. 54). Available from the National Institute for Health and Care Excellence (NICE) Web site • Mental health problems in people with learning disabilities: prevention, assessment and management. Appendices. London (UK): National Institute for Health and Care Excellence (NICE); 2016 Sep. (NICE guideline; no. 54). Available from the NICE Web site Mental health problems in people with learning disabilities: prevention, assessment and management. Baseline assessment tool. London (UK): National Institute for Health and Care Excellence; 2016 Sep. (NICE guideline; no. 54). Available from the NICE Web site Mental health problems in people with learning disabilities; prevention, assessment and management. Resource impact report. London (UK): National Institute for Health and Care Excellence; 2016 Sep. 10 p. (NICE guideline; no. 54). Available from the NICE Web site Mental health problems in people with learning disabilities: prevention, assessment and management, Resource impact template, London (UK): National Institute for Health and Care Excellence; 2016 Sep. (NICE guideline; no. 54). Available from the NICE Web site • The guidelines manual 2012. London (UK): National Institute for Health and Care Excellence (NICE); 2012 Nov. Available from the NICE Web site • Developing NICE guidelines: the manual. London (UK): National Institute for Health and Care Excellence (NICE); 2014 Oct. Available from the NICE Web site **Patient Resources** The following is available: Mental health problems in people with learning disabilities: prevention, assessment and management. Information for the public. London (UK): National Institute for Health and Care Excellence; 2016 Sep. 10 p. (NICE guideline; no. 54). Available from the National Institute for Health and Care Excellence (NICE) Web site the NICE Web site . Also available in an Easy read version from the NICE Web site Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their

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Guideline Status

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